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ABSTRACT

Confidentiality issues in cooperative relationships between schools and agencies providing services to children and families with special needs are examined. Introductory sections consider the need to share information and the nature of confidentiality restrictions. A section on overall information sharing considers: when to address the confidentiality issue; whom to involve; clarifying reasons to share information; identifying and addressing legal and non-legal issues; and interagency agreements and memoranda of understanding. The next section looks at "informed consent" as the basis of information sharing, examining: whether there should be a common release form; content of release forms; presenting the release form and obtaining consent; who can grant consent; handling situations where consent is difficult to obtain; and the use of structural or staffing arrangements to remove the need for consent. The following sections look at the use of data at an aggregate level and special considerations when using automated systems for information sharing. Guidelines for protecting confidentiality cover staff training, limiting exchange, extra safeguards for particularly sensitive information, and the re-release of information. Briefly noted is the state legislature's role. Appendices provide sample forms, a checklist, federal statutes and regulations, and a list of seven resources. (DB)

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A Joint Publication of

Joining Forces
American Public Welfare Association
Center for Law and Social Policy
Council of Chief State School Officers
and
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INTRODUCTION

Concern about the well-being of children and families is widespread today, and interagency collaboration is attracting a lot of attention as one strategy to enhance and secure that well-being. Increasingly, institutions serving children and families are trying to work together to fill service gaps, reduce duplication, make services more accessible and respond to needs of families, rather than provide fragmented services to individual members.

Inevitably, as they plan and implement collaborative efforts, organizations must address the need to share information about people. This is not an entirely new requirement — indeed, for a long time, organizations have communicated about selected children and families in order to coordinate action, and there are established procedures for the release of information in these circumstances.

What is new in the current environment is a growing expectation that organizations *routinely* will work together to help children and families. Put into practice, this expectation has several implications in the area of information sharing: it means that an exchange of information is likely to be sought in many more cases, that more organizations are likely to be involved in the exchange and that more detailed information may be desired.

Questions that once rarely were asked are now much more common. How can a school know if a child or family about whom it is concerned is already being served by an agency? How can agencies assure that their services are complementary rather than duplicative? How can they reduce the need for individuals to give the same information again and again to multiple workers in multiple agencies?

Yet, despite the seeming value of exchanging information, most of these institutions operate under one or more confidentiality mandates that place constraints on such an exchange. These mandates come from different places, including federal statutes or rules, state statutes or rules, interpretations of the federal or state constitutions and state common law. In addition, even when there is no explicit statutory provision governing the agency, there may be formal or informal codes of professional ethics that affect the willingness of professionals to share information with others.

It is often hard just to identify all of the mandates that govern participating agencies. Even when the mandates are identified, it may be hard to figure out exactly what they mean or how they might or might not apply to the collaborative effort.

When faced with multiple and sometimes unclear confidentiality mandates, some potential collaborators may conclude that the confidentiality requirements make it impossible to proceed with a joint initiative. Others may argue that there must be a way to "get around" the requirements, because the confidentiality provisions couldn't really be intended to apply to schools and agencies working with the best interest of the child or family in mind.

This paper is grounded in a very different philosophy than is represented by either of these extremes — that confidentiality is neither an impenetrable barrier nor something which can be casually disregarded. Based on the experience of practitioners

around the country who are tackling the issue successfully and on our own analysis, we conclude that **it *is* possible to develop means of exchanging information that are effective and practical on a wide scale, while still respecting legitimate rights to privacy**.

In some situations, confidentiality protection may necessitate doing something differently than originally envisioned. But that does not mean the collaboration cannot move forward effectively. As we have talked with people involved in successful interagency endeavors, we repeatedly have found that they are able to accomplish their policy goals *within the law* through flexible and creative responses.

Generally, confidentiality statutes are there for a legitimate reason: so that an individual may receive specific services from a specific institution without making his or her individual or family circumstances a matter of record to anyone other than that institution. While interagency efforts create new interests in information sharing, the underlying concerns that led to enactment of the statutes still must be respected and addressed. The broad challenge is to make interagency efforts work consistent with confidentiality protections.

In most instances, "informed consent" is the unifying principle through which that challenge can be met. A person must voluntarily give his or her consent before information about that person can be released to someone else, and consent must be based on a full understanding of what information will be exchanged, with whom it will be shared and how it will be used. Some of the most promising interagency approaches are ones that affirmatively embrace the idea that informed consent for the release of information is part of empowering the individual as an active participant in resolving personal and family issues.

The application of this principle and some of the specific approaches being used by states and localities are discussed more fully in the remainder of this paper. While they offer a good starting point for readers to use in framing their own guidelines, a caution is also in order. Virtually every jurisdiction and every statute is distinctive in some way, and it would be impossible for a single paper to provide a comprehensive legal analysis applicable in all communities. Moreover, each collaborative will have its own unique features, based on the agencies involved, the specific laws governing those agencies and the goals of the collaborative. Readers of this paper must consider the ideas presented here in the context of the specific statutes and regulations under which they operate and the goals that they are trying to achieve.

WHY SHARE INFORMATION?

Why do schools and agencies need to share information at all? It is useful to step back and ask the question, because the *reason* for sharing information will often affect *what* information is relevant and *how* it needs to be shared.

Sometimes, it is important to communicate specific information about a *particular child or family*. Information sharing may be needed to:

- *Ensure that people are getting the help they need.* A case manager seeking to assure that his or her client is receiving all services for which he or she is eligible needs to know what services the client is receiving, whether services from other agencies have been denied or terminated or what reasons may be preventing receipt of services. An organization wanting to let affected persons know about its services may need some way to identify and contact them.

- *Ensure continuity of services.* Changes in a child's or family's circumstances — a youngster going from elementary to middle school, a family moving to a new home — may mean that a new institution will assume lead responsibility. Information exchange can ease the transition to dealing with new people, minimize the possibility of a gap in service and help assure that progress which has been made is not lost but is the foundation for future work with the child or family.

- *Avoid duplication and achieve efficiency.* For example, each agency may have its own assessment procedures, but if assessment information were shared, Agency B would only need to focus on the gaps (if any) in Agency A's prior assessment. Or, one agency's eligibility information could be used to establish eligibility for another agency's service.

- *Move toward family-focused services.* Problems that a parent or sibling is having may be directly relevant to issues in the life of a child. Yet, one agency may be serving the parent, while the agency serving the child is wholly unaware of the problem.

- *Enforce mandates.* For example, if an agency requires its clients to seek a service or perform an activity, the agency may need information as to whether the client has done what he or she was directed to do.

In other instances, the primary interest is in the use of *aggregate data*, or data reported in such a way that particular individuals' identities will not be known. Information sharing at this level may be needed to:

- *Assess community needs.* For example, information about the changing needs of infants and toddlers may be directly relevant to future demand for education services in the elementary schools.

- *Identify overlapping populations and restructure service delivery arrangements to create an integrated system of supports.* Understanding areas of shared responsibility can be an important motivation and foundation for collaborative action. Over time, information sharing can strengthen these initial relationships and foster the evolution of a well-integrated system.

- *Determine the short- or long-term effectiveness of a program.* For example, if a welfare department is emphasizing high school completion, it may need information about school attendance. Or, an agency offering a service may need follow-up data about the experiences of children with other community agencies in later years in order to gauge the effectiveness of its program.

- *Enhance cross-system accountability.* It may be important to understand whether, over time, referrals lead to services or services lead to hoped-for outcomes.

As the following sections discuss, the issues and approaches sometimes vary, depending on whether the need is for individual or aggregate information sharing.

THE NATURE OF CONFIDENTIALITY RESTRICTIONS

Confidentiality rules are a way to protect people from unwarranted invasions of their privacy and from use of information for a purpose for which it was never intended. The rules also protect people from the repercussions that could result because of negative public attitudes; that is the reason, for example, that rules are particularly stringent with respect to child abuse and neglect, mental health history, human immunodeficiency virus (HIV) status and substance abuse. The basic premise is that information about an individual is given, collected or recorded *for a specific reason* and that, unless there is an overriding justification, the information should not be used for other purposes without the individual's concurrence. Confidentiality rules also protect organizations and their staff from being forced to disclose confidences or to act as agents of law enforcement.

Confidentiality restrictions are not limited to government. A number of professionals — doctors, mental health workers, social workers — may have legal obligations or strong ethical standards that prohibit release of information about a patient, client or student without consent. Again, there is a recognition that people often seek help in a state of vulnerability, that the willingness to describe a situation candidly is essential to the relationship, and that an individual's

How a Mental Health Worker Views Confidentiality . . .

The confidentiality of psychiatric treatment records is steeped not only in the long tradition of confidentiality of medical records generally, but also in the unique concern that information about this kind of treatment is intimate and worthy of special protection.

While state statutory and common laws vary extensively, they generally protect the confidentiality of records of psychiatric treatment against disclosure to third parties, including other government agencies, without the patient's consent. The laws also contain exceptions to the right of confidentiality — for example, for disclosure in court proceedings in certain circumstances, for reporting child abuse and for preventing violent acts to third persons.

Furthermore, waiver of the right to confidentiality is commonly required to qualify for public benefits. For example, a person will not be awarded disability benefits without making otherwise confidential medical records available to the agency.

In recent years, states and localities have grappled with the confidentiality problem where a long-term psychiatric patient living in a community program is rehospitalized for a brief period. The hospital or program, as the case may be, wishes to have immediate access to the patient's records. Some states have enacted laws to permit the exchange of psychiatric records among public mental health agencies, although the practice remains controversial.

In most circumstances, consent remains the best method to deal with confidentiality of records of psychiatric treatment.

willingness to speak freely could be fundamentally impaired if he or she did not have an assurance of confidentiality.

Nonetheless, a confidentiality provision is *not* a blanket prohibition against service providers and school staff talking together to coordinate services. It is simply a protection against sharing information about a person over that person's objection or sharing information that does not serve a specific purpose that is in a child's or family's interest.

While virtually all organizations serving children and families operate with some form of confidentiality requirements, these requirements are rarely identical. One should not assume, therefore, that because something is permissible for Agency A, it is also permissible for Agency B, or that because something was permissible in State A, it will be permissible in State B.

Despite these variations, there are important similarities among provisions. Many confidentiality provisions, for example, will address the following questions:

- What *kind of information* is covered by the statute? For example, a statute may permit release of names but prohibit release of information about services provided.

- What *form of information* is covered? For example, the statute may prohibit release of documentary material but not prohibit oral conversations about services to a client.

- What *exceptions* are present? For example, the statute may identify other entities to whom information can be released or identify specific instances, e.g., danger to health and safety, in which information can be released.

- What *conditions apply to disclosure*? For example, a statute may specifically provide that information may be released only to other agencies with similar standards of confidentiality.

- What is the effect of a *release form*? Many confidentiality provisions provide that an individual can permit information to be shared by signing a release. Can all provisions of the statute be addressed through this release? Does the statute address who must sign the release, what the release must say or how long the release may be in effect?

- *Who holds the right to consent* to release? For example, a statute may specify that in the case of a child under 18, the right to consent is held by the parent.

- What is the *penalty* for violation of the statute? Is there criminal or civil liability? Does the agency risk loss of federal or other funds? Is liability limited to the agency or to the individual who engaged in the unauthorized release?

Keeping this framework in mind can help in understanding limits and exploring alternative approaches. It may be that Agency A cannot provide X and Y, but it can provide Z. Or, it may be that Agency B must adopt standards of confidentiality comparable to those of Agency A or both agencies must use release forms. Or, it may be that a revision of a release form would make a difference. In a few instances, it may be that the problem cannot be addressed within existing law, making it necessary to rethink what the agency wants to do or explore the possibility of changing the law. In any case, the focus should not be: "Can we do it, yes or no?" The focus should be: "How can we find ways to meet legitimate service goals within what is possible under the law?"

DEVELOPING AN APPROACH FOR INFORMATION SHARING

Because staff in most people-serving systems are quite cautious about matters of confidentiality, and because the subject is a complex one, the *process* for reaching agreement on how to share information is often as important as the resulting agreement itself.

Putting Confidentiality in Context: When to Address the Issue

Perhaps the clearest advice we heard from successful collaborators is that working on confidentiality and information sharing should *not* be among the first tasks of a developing collaborative effort. Because the subject is complex and a mutually agreed-upon approach for information sharing is likely to entail compromises, it is important to have working relationships and commitment to joint efforts already firmly in place. The stronger the personal relationships among participants, the more easily confidentiality issues can be addressed. Holding off a bit on the time when the issue is tackled allows a base of trust, mutual understanding and experience working together to be built.

This timing was key in Fulton County, Kentucky, for example. Discussion of confidentiality was delayed until planning for implementation of the Kentucky Integrated Delivery System was well under way. There already had been an initial meeting to explain the program, a survey of community services and gaps and subsequent meetings to expand knowledge of available resources and options to fill gaps. By the time confidentiality was discussed, there was a common basis of understanding and a shared commitment that enabled the schools and participating agencies to construct an information-sharing approach that is working smoothly and effectively. Similarly, in San Diego's New Beginnings initiative, confidentiality and information exchange were addressed not as questions of whether or not collaboration could take place, but as implementation issues once the commitment to collaborate was in place and action planning had begun.

Nonetheless, while it is desirable to postpone an in-depth consideration of the confidentiality issue, participants should be reassured early in the process that the issue *will* be fully addressed in the future. Knowing that the matter is being taken seriously and will not be ignored will help them temporarily set aside concerns and focus on the other aspects of planning for joint action.

Who to Involve in the Process

Once the groundwork is laid and it is clear that a process for interagency information sharing needs to be developed, choices must be made about who should be involved in the process. In making these choices, a balance must be struck between involving all those who are potential stakeholders or who could make a significant contribution and keeping the group from becoming unwieldy.

Besides staff specifically charged to develop policy and procedures for the exchange of information, others whose participation might be helpful include:

- *High-level officials:* An administrator in one state noted that the involvement by cabinet officials in conveying that they

wanted the process to work made a major difference in obtaining agency cooperation. Similarly, a local administrator said that representatives from one participating agency only became committed to the process after receiving clear direction from the agency head.

- *Line managers/staff:* Those who work directly with children and families can help identify questions and concerns that might arise and assess the feasibility and practicality of approaches under consideration.

- *Parents/clients/advocates:* Delaware's Integrated Service Information System (ISIS) will track and monitor children through age 8 who are at risk of developmental delay or disability. Parents of affected children were actively involved in the process of considering what information should be in the system, how the release form should read and how it should be presented.

- *Legislative staff:* Are there staff persons involved with relevant legislative committees who would be interested in participating in a working group? Their involvement may offer insights into legislative intent and sensitize them to issues that may eventually need legislative resolution.

- *Judges:* In some circumstances, the involvement of the judiciary may be appropriate. Generally, it would not be appropriate for judges to be involved in fashioning arrangements where the courts could ultimately be forced to rule on the legality of the arrangements. But if, for example, one aspect of an interagency collaborative involves the issue of access to juvenile court records, the involvement of judges could be essential.

- *Management information system personnel:* A major cluster of issues often revolves around different options for what an automated system can do and what kinds of security protections can and should be built into a system. Individuals responsible for setting automated systems policy and for the broad design of systems can help think through the use of computers in an overall information-sharing approach.

- *Attorneys:* Since there are legal boundaries and stipulations affecting information sharing among organizations, legal advice is important in framing an acceptable approach. (See next page — Identifying and Addressing Legal Issues)

- *Other community perspectives:* When Delaware was designing its ISIS system for tracking children age 0 to 8, an advisory committee included a pediatrician, early childhood development specialist and early intervention nurse, each of whom added distinct perspectives.

Clarifying the Reasons to Share Information

In an earlier section of this paper, we discussed some of the reasons why information sharing may be sought. Agreeing on the specific reasons that guide a particular collaborative effort is an important foundation for subsequent deliberations. Sometimes, discussions about confidentiality begin immediately with the content of or form in which information is being sought. If that particular content or form is unacceptable, the discussions may founder. But if all have agreed on the basic objective, it is more likely that participants, faced with an unacceptable approach, will move on to find an alternative that is more workable and accomplishes the same goal.

A serious discussion about and basic agreement on the reasons for information sharing also offer a valuable protection. Processes sometimes take on a momentum of their own, as people become committed to "com-

plete information sharing" or intrigued by the theoretical capabilities of a system. Articulating specifically why sharing is needed can help keep the conversation focused and limited, setting a responsible framework in which to identify specific information elements to be shared and who needs to have access to accomplish the purpose.

For example, case managers may need to know who else is working with a child or family so that services can be coordinated. But they may not need to know every detail of the other agency's intervention. Moreover, a caseworker may feel much more comfortable engaging in a focused conversation than in making all his or her records about a case available to unknown persons at unspecified agencies. Accordingly, a system that makes available names of other agencies and workers who provide services to the family may be both sufficient and most acceptable, after which workers could use professional judgment in providing other information.

Identifying and Addressing Legal Issues

After there is general agreement on what information people wish to share and why, a careful review of applicable and potentially applicable statutes, regulations, constitutional provisions and court decisions is needed. We emphasize this need to go beyond review simply of the statutory confidentiality provisions and associated rules. The courts sometimes interpret the language of a statute or regulation in ways that might be surprising given the language of the provision. For example, federal regulations for the Aid to Families with Dependent Children program seem to say that state law can permit the publication of lists or names of applicants and recipients. But a federal court has held that a state that made such a listing available violated the Social Security Act.[1] Knowing how the courts have interpreted the language of the law — or similar language — is necessary to be sure that the collaborative effort is not going in a direction that the courts have already precluded.

Court rulings also may create additional "law" governing confidentiality. For example, even though there is no specific statute, the courts may have ruled that an individual can bring a damage action for unauthorized release of information. A professional who releases information without permission might risk a malpractice action under such rulings. For these reasons, it is essential to look at court decisions as well as statutes and regulations when deciding what is and is not permissible.

The review of statutes and related provisions and actions should include one or more attorneys. Typically, each agency has its own attorney or legal staff providing advice about its particular statutory scheme. While such attorneys may offer substantial expertise, it may also be useful to designate a "lead attorney" or have an attorney whose client is the collaborative and whose job it is to synthesize input from the various sources and look at issues from the perspective of the collaborative as a whole. This is a way to avoid a scenario in which the broader group of collaborators, most of whom will not be attorneys, is left to sort out multiple, and possibly conflicting, legal interpretations.

Whether there is a single attorney or multiple attorneys involved in the process, sometimes those who are not attorneys may feel frustrated by legal advice that seems overly cautious or constraining. At this point, it is useful to remember that confidentiality is a very delicate area in which caution is well taken. The following may also help attorneys and other participants in the collaborative work together effectively to find an acceptable approach:

- Be able to frame specific questions based on what you want to do. Some of the most frustrating experiences for both administrator and attorney occur when the

attorney is asked to summarize "the law about confidentiality" for an agency. That is a sweeping request that may include a lot of material that is completely irrelevant to what you want to do. The real question may not be, "What's the law about confidentiality and the schools?" Rather, you want to know, "When can a teacher talk with a case manager about Johnny's behavior in the classroom?" If you can initially identify what information needs to be shared, with whom it needs to be shared and why it needs to be shared, there is a much better chance that the attorney's findings will be relevant to your needs.

- Recognize that the attorney's job is ultimately to protect the client, and this sometimes leads to cautious advice. Often, the law doesn't address the specific situation you have in mind. For example, the law may prohibit release of records without consent but be silent about whether a caseworker can have a conversation based on the contents of the records without consent. When the law is not explicit, what should you do? In this situation, the attorney may conclude that you could risk getting sued if you proceed without use of release forms but do not have the same risk if you rely on release forms. Unless the law is exceptionally clear, the attorney is likely to recommend a cautious course, because that is the course that is least likely to lead to legal problems.

Identifying and Addressing Non-Legal Issues

Participants in a collaborative endeavor may have concerns about information sharing that go beyond what is and is not permissible under confidentiality statutes and rules. Sometimes, these non-legal issues can pose seeming barriers as significant as legal constraints.

Among the most common are:

- *Professional ethics:* In some instances, professionals may indicate that "professional standards" preclude releasing information. Even though there may be no express statutory prohibition, the professional may have both ethical and legal concerns. In addition to risking damage to the relationship with the client or student, could he or she risk being sued for improper disclosure of information? A viable approach for exchanging information must acknowledge and accommodate these concerns. For example, there may be a particular concern that consent to release of information be "informed." Allowing representatives of the professional group to participate actively in designing the protocols for obtaining release could provide needed assurance that there is informed consent. Similarly, the question of how much information is routinely accessible may be critical. There will likely be greater willingness to accept an approach in which the only routinely accessible information is whether the individual or family is being served in a system, with release of additional information being subject to exercise of professional judgment.

- *Long-standing practice:* Organizations may have established ways of operating that are accepted simply because "things have always been done that way." Staff may assume that these policies, procedures or practices derive their authority from laws or regulations, even though many do not. Clarifying what is and is not actually required will be an important first step to changing these practices. But it may be equally important to provide an alternative approach that satisfies the purposes met by the previous practice and to allow sufficient time for staff to become comfortable with the new approach.

- *Lack of understanding:* Staff may be resistant if they do not understand why information is being requested. We heard of several instances in which it was difficult

Confidentiality and Health Care . . .

Historically, confidentiality has been very important within the health care system both as a matter of law and as a matter of ethics. The Hippocratic oath pledges the health professional to keep medical information confidential. In its original form, however, the commitment to confidentiality applied only for "those things that ought not to be spread abroad," leaving open the question of what ought to be spread. In an earlier time, physicians and professional associations often interpreted this requirement paternalistically, thus permitting disclosure whenever the physician believed it would benefit the patient or client (even if the client did not agree). The American Medical Association (AMA), for instance, until 1981 specifically authorized disclosures when it was deemed in the interests of the patient.

Over the past 20 years, ethical and legal interpretations have shifted. Now, the professional associations — at least in their official policies — have dropped the paternalistic criterion for disclosure. It is widely acknowledged in both ethical and legal frameworks that only two conditions justify disclosing information: when the patient gives express consent or when there are overriding social considerations.

The overriding social considerations include those cases, and perhaps only those cases, in which the law requires or authorizes disclosure. The AMA identifies as an example the case in which a patient threatens to inflict serious bodily harm to another person and there is a reasonable probability that the patient may carry out the threat. That seems to be in accord with current American law. Other examples of disclosure that may be in accord with the law include use of information for statistical research, for insurance and accounting purposes, or when ordered by a court.

to get staff to share information — even when the release was clearly authorized — apparently because they did not understand or had questions about why the information was being sought or what it would be used for. Without that understanding, they tended to view the proposed information sharing as simply another burden on their time or a potential intrusion into their relationship with their students or clients. Good training and written materials that explain in advance the information-sharing approach and its advantages for children and families are an effective way to mitigate much of this resistance. Similarly, feedback about how information exchange helped a specific child or family can increase future readiness to be forthcoming with information. Over time, it also is likely that greater interaction among institutions will deepen the general understanding and acceptance the staffs of those institutions have of one another's mission and operations.

- *Objections to the proposed use:* Resistance also may come because of concerns about how the information will be used. There may be a fear that information on a client will be used for punitive purposes. Iowa is exploring the possibility of stipulating that shared information cannot be used for punitive purposes. One model for this type of approach might be drawn from federal provisions concerning confidentiality of alcohol and drug abuse records. The law expressly provides that, except as authorized by court order for good cause, no record can be used to initiate or substantiate a criminal charge against or conduct an investigation of a patient.[2]

- *Need for trust:* A common theme uncovered in our conversations was that personal relationships are as important, if not more important, than any procedures. Even when an individual clearly has consented to the sharing of information, some staff simply will not be comfortable releasing information to a person or agency whom they do not know and trust. Developing trust cannot be the entire answer because information sharing must be based on what is legally permissible and must be conducted in a responsible, structured manner. But, fostering good working relationships among the staffs of collaborating organizations is essential to assure that they are willing to use the procedures that are developed.

Interagency Agreements and Memoranda of Understanding

Most sites we contacted have signed an interagency agreement or memorandum of understanding that documents at least the broad parameters of the agreed-upon approach to sharing of information. In part reflecting the expectation that joint action and related information exchange will become a *routine* part of assisting children and families, these documents formalize organization-to-organization connections, complementing specific staff directives that may be issued by each organization or by the group of organizations collectively.

Sometimes, the agreement focuses only on information sharing. Iowa, for example, has a formal agreement between the Department of Human Services and the Department of Education regarding an exchange of information to facilitate outreach by adult education programs to welfare recipients who lack a high school diploma. Often, though, the approach to information sharing is only one component of a broader agreement regarding collaboration among the participating entities. San Diego, for example, is developing a memorandum of agreement that will define the purpose and responsibilities of the "extended team" of agency-based staff that will support the school-based service center; plans with respect to confidentiality will be presented as part of that agreement. Even in this case, though, more specific agreements may be formulated about particular aspects of information sharing, e.g., automated systems matches.

"INFORMED CONSENT": THE FOUNDATION OF INFORMATION SHARING

As a general rule, exchanging individually identifiable information requires consent from the affected individual or a designated alternate, such as a parent consenting for a child. Consent must be given voluntarily and must be "informed" — that is, the individual must understand fully what information will be exchanged, with whom it will be shared and how it will be used.[3] Consent must be documented in writing, usually on a signed release form.

While all the organizations in a collaborative effort may be bound by these common principles, each is likely to be responding to a different governing statute and to have a different set of rules about consent. Sometimes, a law may specify what must happen in the release process, e.g., who must sign, what the document must say and what is the scope of permissible release. But often, the law simply says that certain information may not be released without consent, and a school or agency will have developed its own procedures to implement that concept according to its own interpretation. There may be no consistency among different organizations' policies and forms, and forms that are entirely adequate for one organization's internal purposes may be unacceptable to another.

Thus, developing an information-sharing approach grounded in "informed consent" that can be systematically and efficiently used by all collaborating organizations will mean harmonizing multiple requirements, as well as assuring essential protections for children and families.

Should There Be a Common Release Form?

There are a variety of ways in which consent to release of information could be obtained. Every agency could develop or use its own release form. Or, agencies might work together to develop a common release form. Or, these approaches might be combined, with some agencies agreeing to use a common form, while others wish to continue using a form specific to their needs.

Although each of these approaches is being used successfully, in general, using a single form rather than multiple forms would seem easiest. From the perspective of the participating organizations, having a single form would remove any question at the staff level about whether a form used by one agency to obtain release is acceptable to the agency from which information is being sought. A single form is also less complicated and burdensome than multiple forms for the individual or family seeking services.

A number of collaboratives have had success in developing a common release form. For example, the Contra Costa Interagency Family Preservation Program in California developed a single short release form that permits sharing of information among members of the Interagency Referral Committee for the purpose of service planning (see Appendix 1). The Linn County Youth Services Teams in Oregon also use a common parent authorization form. Like the Contra Costa form, Linn County's lists the agencies involved in the team. The form also explains that "[r]epresentatives of these agencies will

meet and share information regarding your child at scheduled planning and review meetings" and describes the information to be disclosed and exchanged (see Appendix 1).

How viable is use of a common release form? While different laws may have different requirements, experience thus far indicates that it is quite possible to find language and agree on content that will be acceptable to all. For example, one set of regulations may expressly require a release form to provide a termination point, and another set of regulations may be silent on the point. When that happens, both requirements can be satisfied by assuring that whatever is required by any of the organizations be incorporated. In theory, this could lead to a long and unwieldy form, but in practice the number of differences arising from mandates appear relatively few, and the common forms that have been developed are of an easily manageable length.

The Content of Release Forms

As cautioned in the introduction to this paper, each set of collaborating organizations must develop policies, procedures and forms that fit the particular mandates under which its members operate and the purposes for which it is seeking to exchange information. It is impossible, therefore, to prescribe an "ideal" release form. Nonetheless, we enclose in Appendix 1 samples of forms now in use by collaborative efforts and outline some general guidelines below to help readers begin to consider what their own forms should contain.

From a broad perspective, a basic principle for developing release forms is to avoid "blanket releases" that are completely open-ended on matters like the time period covered, the information to be exchanged and the reasons for the exchange. Blanket releases are the most likely to prove troubling to the person from whom consent is being sought and may be legally vulnerable.

It is also important that the language in release forms be simple and straightforward. A first impulse may be to track statutory language, but the statutory language may be incomprehensible to both staff and the person presented with the form. There is a need for balance between conveying what has to be conveyed and using language that people can understand. Field testing a form can give valuable feedback about what people do and don't understand.

For those whose primary language is not English, it is desirable to have forms printed in the language with which they are most comfortable, so that they truly can understand the nature of the release.

Among the more specific elements a release form might contain are:

- *Agencies or organizations permitted to release and receive information.* Before today's multi-agency collaborative efforts became popular, consent often was given simply for one organization to provide information to a single other organization. Now, the picture is more complex, and exchange may involve multiple organizations that will be either or both providers and recipients of information.

  A release form needs to specify who these organizations are. In some sites, the list includes all agencies who are members of an interagency team, whether or not those agencies are providing service to that specific individual or family. For others, the listing of agencies may be those from whom the person or family is currently getting or seeking services; if so, there needs to be a way to add on additional agencies over time.

  Some collaborative efforts, eager to involve all agencies serving a child or family but concerned that the family may not

be able to readily identify all providers, are exploring a two-tiered approach to releases. An initial release allows agencies to report whether or not they are providing services; subsequent releases then are sought to allow agencies that are found to be working with the child or family to release more detailed information.

If a single release form is used for multiple agencies, the person needs some way to indicate if there are limits to his or her consent — for example, that information may be exchanged between Agencies A and B, but not between Agencies A and C. In Linn County, Oregon, the Youth Services Team Authorization for Release form contains a listing of the agencies participating on the team. A parent or child signing the release form is given an opportunity to scratch out the names of any participating agency with which they do not want sharing of information to occur.

It may also be useful for the form to state clearly that information will not be shared with organizations other than those authorized through the specific release being signed, unless additional consent is sought. This could be especially important, for example, to undocumented individuals who may be concerned about communication with the U.S. Immigration and Naturalization Service.[4]

- *Who is covered by the release.* When the release concerns a particular individual, this is straightforward. But if a parent is signing for family members, the form should specifically identify to whom the release applies — not everyone has the same understanding of who is in the "family."

- *Kind of information to be released.* Some forms cover any or all of the materials in the possession of the agencies being authorized to release information. Others set limits of varying degree: limits may be quite broad — for example, exchanged information may be limited to that which is "pertinent" to the concerns being addressed by the interagency team — or the kind of information to be shared may be described very specifically. There is a trade-off here. When the description of information to be shared is more general and comprehensive, it is more likely to incorporate all situations that may arise. On the other hand, it is also more likely to raise concerns on the part of both affected individuals and some collaborative participants about the potential for misuse.

- *How information will be used and for what purpose.* A number of the interagency efforts are attempting to be as specific as possible about the purpose for which information will be used and under what circumstances. Forms may specify whether written materials will be exchanged or whether the exchange will be oral only. This is also an opportunity to obtain consent for using client-specific information to generate aggregate data — for example, if there is an interest in evaluating the impact or effectiveness of particular services. Sometimes, the statement of purpose is combined with an explanation of the benefits of information sharing (discussed below). A useful check that the information-sharing process is not becoming too broad-reaching is to assure that the *kind* of information requested suits the *purpose* for which it is intended.

- *Termination date.* Many statutes or regulations are silent about termination dates. Others specify that consent must be for a limited period. Federal regulations governing releases for alcohol and drug abuse patients, for example, require the form to specify a termination point and provide that the selected point must ensure that the consent will last no longer than reasonably necessary to serve the purpose for which it is given.[5]

In some instances, there may be a "natural" termination date, e.g., while Ms. Smith is in the program, while Johnny is in the XYZ School, until the next reassessment or redetermination of eligibility. In Fulton County, Kentucky, the school-based service program makes its release forms valid only for the school year. The Linn County Youth Services Teams in Oregon take the same approach.

The termination point might not necessarily be a specific date. The Consent to Exchange developed by the San Bernardino County Children's Network provides space to specify the termination point, which could be a specific date or a specific event or condition.

Alcohol and drug abuse regulations also require a statement that the consent is subject to revocation at any time, except to the extent that the program or person who is to make disclosure has already acted in reliance on it.[6] While many laws do not contain the same express requirement, a clear and explicit statement that consent may be revoked at any time may help the individual better understand his or her rights and the implications of signing the release.

If a termination date is specified on the release form, there needs to be a process for ensuring that the release is either renewed or ceases to be effective after that date, and that each affected agency is aware of the status.

- *Benefits of information sharing.* Someone may be more willing to sign a consent form if the form clearly explains how he or she will be helped by doing so. Although much of this explanation is probably best done in conversation, as described in the next section of this paper, it may be useful to have at least a summary statement on the form itself.

- *Consequences of not authorizing release.* Consider whether the form should also include an accurate, nonthreatening statement about what will happen if the individual does not sign, i.e., "If you do not consent, you will still be eligible for program services. However, your X worker and Y worker will not be able to talk to each other about how they can work together to help you."

Presenting the Release Form and Obtaining Consent

Interagency collaborative efforts must agree not only on the content of release forms, but also on who is responsible for presenting the form and obtaining consent.

If it has been determined that each agency will use its own form, then usually each agency will secure consent individually. The decision to use a common form opens other options, however. In the latter situation, it becomes feasible, if the form is appropriately constructed and participating organizations agree, for the consenting individual to sign only one form. Among the sites we contacted, those using a common form usually take this latter approach. Whichever organization first determines that collaboration is indicated with respect to a particular child or family is responsible for securing a release so that the collaboration can proceed. If there is an integrated intake process — in which an individual or family goes through one application process that provides access to a range of services from various institutions — then consent on either a single form or on multiple forms can usually be obtained as part of that process.

Even if it is agreed that the consenting individual need sign only one form, each agency will likely need or want hard-copy documentation that consent has been granted, so there needs to be a process for circulating copies of the release.

In addition to the issue of who is responsible for presenting the release form and obtaining consent, the collaborators with whom we spoke repeatedly cited the importance of *how* the request is presented to the individual whose consent is being sought. Timing is one element — it helps to wait until a relationship of trust has been established before seeking consent to release — as is a clear, simple and straightforward explanation of what is being asked and why and an opportunity for the person to ask questions.

Virtually everyone told us that, when those asked for consent understand the desire of schools and agencies to help them and how information will be handled, the consent is readily given. The Contra Costa Interagency Family Preservation Program, for example, recalls that in serving 150 families, there have been only two instances in which consent was refused. Similarly, the Linn County, Oregon Youth Services Teams have obtained consent in more than 90% of their cases. In fact, many effective collaborators find that assuring that a person understands why consent is being sought and what the result will be has value beyond simply obtaining the release. The individual or family to be helped becomes an active and contributing part of the planning process.

To ensure that people do understand what they are being asked to sign, the staff person presenting the form must himself or herself understand what the form says and means, understand the benefits of consent and any consequences of declining to sign and be able to present this information clearly. For its Integrated Service Information System, Delaware is developing a checklist to guide staff in strengthening client understanding (see Appendix 2 for current version). As envisioned, the staff person will systematically explain the nature and purpose of the system, how it will benefit children and their families, the kind of information in the system, who will be allowed to view it and the parent's right to know who is looking at a child's records. After this information has been presented, the parent would be asked to explain his or her understanding of the system and how the family might benefit *before* signing a consent.

Who Can Grant Consent?

An adult usually must grant consent for release of information about himself or herself, unless there is a court determination that a release can be made without consent or on the basis of consent by someone else.

Generally speaking, parents can or must authorize release of information about children. Some collaborative efforts such as the New Futures program in Savannah, Georgia, have experienced problems when parents are absent or unavailable, and it is not clear who is authorized to consent to release. Who has authority to sign a release will likely depend on state law. However, if there is uncertainty about whether the custodian has authority to sign, there may be the same uncertainty about whether the custodian could consent to medical care. Accordingly, resolving the child's status may be important for more reasons than just ensuring that there is consent to information sharing.

Although in many instances the law may expressly provide that parental consent is sufficient to release information about a child under 18, a number of sites have found it valuable to obtain the consent of the child as well. This step can help the child feel a stronger sense of involvement and ownership over the services being provided, lessen parent-child conflict and help alleviate any fears of the child that parents and the institutions are allied against him or her.

The idea of obtaining a child's consent is suggested in federal rules affecting special education. These rules provide that a state education agency must have policies and procedures regarding the extent to which children are afforded rights of privacy

similar to those afforded to parents, taking into consideration the age of the child and type or severity of disability.[7] The Youth Services Teams in Linn County, Oregon, offer an example of similar rules being applied more broadly to many children served by the collaborative endeavor. The teams seek the written consent of any child age 12 and over, in addition to the consent of the appropriate adult. If the child does not sign the consent, policies provide that the Juvenile Department will not participate in any information sharing. To date, no child has declined to consent.

Handling Situations Where Consent Is Hard or Impossible to Obtain

In what appears to be a small number of cases, a person simply does not want to sign a consent. Why? Parents may fear that the process will be used to take their children away from them. An adolescent receiving counseling because of maltreatment at home may not want that known at school, which is the one place where he or she has a strong positive image as a leader and achiever. In other instances, an individual has had a bad experience with one or more agencies in the past and does not want information to be shared with persons he or she does not trust. Occasionally, there may be fear that the parent or child is vulnerable because of illegal activity.

If consent is withheld, it may be useful to try to determine — without exerting pressure or requiring that a reason be given — why a person is refusing. There may be a legitimate concern that ought to be considered by the involved agencies in future planning.

Even when there is no consent, there may be statutory provision for the sharing of some information — for example, if there is reason to believe an individual may be dangerous to himself or herself or to others. Confidentiality provisions often have a "health or safety" provision, i.e., a section allowing an exception to required consent where necessary to protect health or safety in an emergency.[8] Since the collaborating organizations cannot wait for their attorneys to research "emergency" exceptions while an emergency is occurring, it may be helpful to pull together each agency's emergency exceptions and any interpretations of those exceptions as part of developing the overall information-sharing process.

In cases where a person refuses to consent and "health and safety" exceptions do not apply, there needs to be a way of accommodating his or her choice because someone cannot be compelled to waive a right that he or she has under federal or state law. Moreover, for publicly funded services, it is unlikely that the state can permissibly deny an otherwise available service because the individual chooses to exercise his or her confidentiality rights.

What can be done when an individual refuses to consent? An approach used by the Linn County, Oregon Youth Services Teams is to hold "generic staffings." In these interagency team meetings, a caseworker presents the case of the non-consenting individual for group consideration and advice, but names and all identifying information are withheld, so that the individual's confidentiality rights are not compromised.

Can Certain Structural or Staffing Arrangements Remove the Need for Consent?

Among the characteristics of today's collaborative efforts are significant changes in where services are provided and in the administrative structures under which staff operate. Outposting and co-location of staff, interagency teams and even governing bodies that bring staff together in a new entity are increasingly common. What effect do these arrangements have on exchanging information and the need to secure consent from persons being served? The answer to that is not entirely clear, although most

A Child Welfare Worker's View of Confidentiality . . .

Child welfare records contain some of the most private and personal information the government can maintain on a family. Recipients of child welfare services — which include general social services to families with children, child abuse and neglect services (often called protective services), foster care and adoption — are often concerned that information about them may be released to others. A parent may worry, for example, that a confirmed child abuse report could cost him or her a security clearance. At the same time, other agencies or professionals who serve the same children often are frustrated by their inability to have access to the information that the child welfare system maintains. A child's therapist may, for example, feel stymied by an inability to obtain information about the parent's compliance with child welfare services directives.

Federal and state laws generally regulate access to child welfare records, making the records confidential and restricting release without the client's written consent. The Federal Child Abuse and Prevention and Treatment Act (42 U.S.C. §5101 *et seq*) seeks to protect the rights of the child and of the child's parents or guardians by making federal funding contingent on a state's providing "by statute that all records concerning reports and reports of child abuse and neglect are confidential and that their unauthorized disclosure is a criminal offense." A state may, however, "authorize by statute disclosure to any or all" of certain specifically named persons and agencies "under limitation and procedures the state determines" [45 C.F.R. 1340.14(i)]. The exceptions primarily include persons involved in investigations or service delivery related to abuse and neglect. The regulations do not provide for access to the general public, the parent's employer or others without a valid need for information in order to assist the child or family. Additional persons or agencies may receive access with the client's written consent or pursuant to a court order.

In addition to the rights of the child and family, the confidentiality rights of the individual making a good faith report of suspected child abuse or neglect must be protected. Unless the reporter consents to release, his or her name is to be kept confidential from everyone, including the child and family who are the subject of the report.

sites we consulted appear to be relying heavily on formal releases when there is any information flow that might be construed as external to an agency.

There is precedent in practice for using structural arrangements as a way to facilitate exchange. For a number of years, for example, some communities have been using "treatment teams," which include representatives from schools and other agencies, to handle selected child abuse cases. As members of the team, staff from sectors other than child welfare are considered to be bound by the same confidentiality rules as child welfare staff and thereby are qualified to receive information as needed. Sid Gardner and Katherine Kates[9] observe that some places actually pay a modest amount to members of the team, in part to establish that they are "employees" of the child welfare agency.

While a similar philosophy underlies some current proposals to broaden free flow of information by "deputizing" staff in another agency or creating a "super-organization" that brings everyone under one roof, these approaches do not seem to be the norm. Rather, although new organizational arrangements are making information sharing easier because the procedures and trust are in place, the basic "rules" remain the same — whenever personal information is to be released to someone other than employees of an agency, consent is required.

Of course, staff participating on an interagency team or working at a site other than their own agency still have available to them, within established rules and procedures, information about a child or family that is maintained by their *own* agency. Thus, in a Detroit effort that placed workers from the Department of Social Services (DSS) in a school to work with truant children and their families, the outstationed workers were readily able to obtain information about public assistance status and related benefits, since they remained DSS employees. Releases were needed, however, for the workers to see the children's school records. Had those workers become employees of the school, the school records would have been open to them, but they would have needed releases to obtain information from DSS.

A somewhat more complex situation is raised by "new" agencies that are created through some combination of existing agencies or resources. The Prince George's County, Maryland Commission for Families, for example, is financed through pooled funds from the Departments of Human Resources, Health and Mental Hygiene, Education, and Juvenile Justice, and its staff have been redeployed from those agenices. In this situation, for the purposes of confidentiality, the commission is considered to be a different entity than the participating organizations, and clients being served by the commission are asked to sign releases so that the commission staff can obtain information about them from the other organizations. Similarly, the school-based service center created by San Diego's New Beginnings initiative, which also draws on redeployed dollars and staff, obtains releases from clients before information from participating agencies is placed in the school-based center files.

USING DATA AT AN AGGREGATE LEVEL

As collaborative efforts expand, interest is growing in exchanging information not only to improve service delivery for individual children and families, but also to address broader issues and to manage and improve the community's overall structure and approach for helping its citizens. Policymakers and planners are asking questions such as: How many families are being served by more than one system? What are the characteristics of those families? Where are there gaps in service? What are the outcomes for families referred to certain services?

For these purposes, information about service needs and service delivery usually is sought at an aggregate level, i.e., information reported in such a way that particular individuals' identities will not be known. Is individual consent needed to use data in this way? That is an issue on which there are differences of opinion about what is permissible — differences that may well be

Confidentiality in Schools . . .

The enactment of the Federal Education Rights and Privacy Act (FERPA) in 1974 has had an enormous effect on how schools treat and think about school records. The law has two major features: it limits who can see student records without a parent's consent, and it provides for a parent's right to see a child's school records. When a child turns 18, the rights that were previously available to the child's parents become available to the 18-year-old. State law may create more rights for parents and children, but any school receiving federal education funding has to comply with the FERPA requirements.

The guiding principle for release of student records under FERPA is parental consent. The law broadly defines "educational records" and, with limited exceptions, prohibits a school from disclosing those records without written consent. The limited exceptions generally involve release to other school officials or for other education-related purposes.

Under FERPA, there is a narrow category of information called "directory information" that a school can release without written consent. "Directory information" includes a student's name, address, telephone number, date and place of birth and similar types of information. Directory information is considered information that would not generally be considered harmful or an invasion of privacy if disclosed. Even in the case of directory information, a parent can file a written objection to release of the information.

Because of FERPA's broad scope, an initiative that seeks to share education records with other agencies must involve and obtain the consent of parents of affected children. And, because parents have the rights to see school records, the initiative must recognize that information provided to the schools by other collaborative agencies may become available to parents if it is recorded in school records.

resolved as greater experience is gained, but that at present create some ambiguity for collaborating organizations.

On the one hand, based on our research, it appears that the distinction between exchanging data for use at an aggregate level and for individual service delivery is too fine to create a *general exception* to confidentiality provisions. In part, concern arises because, although individual identities may be hidden in the final aggregate-level report, the source material from which the report is prepared generally *will* include identifiable data. As a consequence, there is some risk that those identities could be exposed. Moreover, there may be a question as to whether or not an individual would agree with the purpose for which aggregate-level data are to be used. Ordinarily, if the original material is protected by confidentiality rules, it would be expected that individual consent for its use by an outside entity should be obtained.

However, there appear to be certain conditions under which exchange without specific consent may be possible. Sometimes, for example, there is an express statutory or regulatory provision authorizing release of information for *research purposes,* a category that a number of sites believe includes cross-agency efforts to identify service gaps and measure outcomes. An instance is the Federal Education Rights and Privacy Act regulations, which allow disclosure for certain studies: to develop, validate or administer predictive tests; to administer student aid programs; or to improve instruction. To be acceptable under these provisions, the study must be conducted in a way that does not permit personal identification of parents and students by anyone other than representatives of the organization doing the study. And the information must be destroyed when no longer needed for the purposes for which the study was conducted.[10]

Confidentiality Through the Eyes of a Welfare Caseworker . . .

Since enactment of the Aid to Families with Dependent Children (AFDC) Program, there have been concerns about harm that could flow from the misuse of information in AFDC case files, or even about releasing the basic fact that an individual receives AFDC. An individual must provide detailed and highly personal information about her finances and family status in order to get assistance. Many people in need might decline that assistance if they believed that others in the community could get ready access to the information.

An individual may want to prevent disclosure of her status as an AFDC recipient. Some people fear that a landlord will not rent to them or an employer will not hire them if it is known that they receive welfare. Some parents do not want their children to know they receive welfare. In one case, AFDC recipients who had been abused by former boyfriends or spouses charged that the former abusers were trying to get information from welfare files to locate them.

To prevent wrongful release of welfare information, federal law requires all states to safeguard information concerning AFDC applicants and recipients. Information can be released (among other reasons) for purposes "directly connected with" determining eligibility and assistance for AFDC or any other federal or federally assisted program that provides assistance on the basis of need. When information is released, it must be to persons or agencies subject to standards of confidentiality comparable to the welfare agency.

Because of the long history of welfare confidentiality protections, state and local welfare agencies are generally accustomed to relying on use of release forms and client consent whenever an outside agency seeks client information.

If similar kinds of management controls were imposed on other exchanges of individually identifiable data for the purpose of preparing aggregate reports, would these exchanges be acceptable, even though there is no express provision? For example, would an exchange be permissible if it took place under tightly controlled conditions such as the following: There is only a tape-to-tape match by computer; only a few people who are carefully trained about the rules and their responsibilities have access to the tapes; and the tapes are promptly destroyed or returned to the originating organizations once a match is complete? Unfortunately, most of the applicable statutes and regulations are silent on this point, and there is insufficient experience and case law to be certain how a court might rule if the exchange were challenged. However, it does seem that the acceptability would be made more likely if safeguards were incorporated to minimize any risk that individually identifiable information could be released.[11]

Other creative and practical approaches that seem promising as alternatives to having to secure consent from all affected parties are built around a process in which protected information is never actually released to another organization. For example, suppose there is an interest in finding out what proportion of students in a school live in families receiving Aid to Families with Dependent Children (AFDC). The AFDC records are subject to federal regulations that prohibit their release to the schools unless there is consent. But the names of children in the school are "directory information" that does not fall within the protections of the Federal Education Rights and Privacy Act. So, there would be no barrier against the school providing names to the welfare department, and the welfare department using that information to report back the proportion, but not names, of students who are AFDC recipients.[12]

Most of the conditions and approaches just discussed deal with the concern about whether or not individual identities might become known. As noted above, there also is some concern that exchanging data without specific release does not permit an individual to decide if he or she agrees with the purpose for which information is to be used. For example, someone might agree with a data match designed to assure that schools with a large number of low-income children receive extra funding, but might not agree with a data match to try to correlate genetic data and race. One approach which has been suggested to address this issue is the application, before exchange, of a "reasonable person" test — i.e., the participating organizations make a determination that a reasonable person in the group about which data is to be exchanged would not object to having the data transmitted without further permission.[13]

In applying a "reasonable person" test and considering other questions with respect to using aggregate data without first obtaining specific consent, those developing collaborative efforts may find it useful to consult with their state's Institutional Review Board, an entity which is required under federal regulations for research involving human subjects funded in whole or in part by funds from the U.S. Department of Health and Human Services.[14] This is done in Florida, for example, where the secretary of the Department of Health and Rehabilitative Services, in approving release of confidential information for research purposes as permitted by state statute, is guided by the policy and procedures of the Review Council for Human Subjects.

To summarize, there are some sound reasons for wanting to exchange data for use at an aggregate level without obtaining individual consent and, in certain cases, approaches that seem to offer reasonable protections when doing so. At the same

time, it is clear that this is an area that will need further exploration as interagency collaboration expands and that may require future legislative or regulatory action to establish acceptable guidelines.

SPECIAL CONSIDERATIONS WHEN AUTOMATED SYSTEMS ARE USED FOR INFORMATION SHARING

Automated systems offer a powerful tool for matching data and exchanging information. But that capacity also carries special risks in the delicate area of confidentiality. Security of records is one risk, since information contained on a computer may be more broadly accessible than a paper file, unless there are special provisions made. Another risk derives from the ease with which data manipulation can be done on computers. Simply because the information *can* be easily generated or obtained does not mean that it *should* be. When data manipulation had to be done manually, the extensive labor involved usually led people to stop and think twice before deciding that the result would be worth the effort. Much of that workload is eliminated through the use of computers, and so one source of caution about information sharing has been removed. It is therefore especially important in an automated environment to ask and answer the questions suggested elsewhere in this paper about *why* information is needed and *what* information is to be exchanged.

Limits on access to information in the computer, as well as on input and output, are also ways that states and communities are balancing the advantages and risks of automated systems:

- *Limit access to what is in the system.* Any shared system must be structured so that access is limited, based on the extent to which consent has been provided or authorization exists. Where consent or authorization is lacking, staff should not be able to obtain access to protected client information. In Florida's Santa Rosa County, the school system and public human service agency are using a common computer-managed database, but staff in each organization are assigned passwords that control access according to whether or not release of information to that person is authorized. For this district, using computers has resulted in easier and faster exchange of information when that exchange is appropriate, but adoption of an automated approach itself has not changed who has access to what.

- *Limit the data that are in a system.* Security risks are reduced if protected data simply are not put into the shared system in the first place. Delaware has determined that it would like schools that are concerned about a particular student to be aware that a human service agency is working with the student and/or his or her family, but they do not want additional specific information to be broadly available. The state, therefore, is exploring the idea of adding client and worker names to a school district's automated system, so that school personnel will know whom to call if they have a concern. But since no other information about the client or services being provided would be in the system, release of any specific information would be subject to the worker's professional judgment.

- *Limit the data that can be retrieved from the system.* Particularly when data are sought at an aggregated level, it may be possible to construct the system so that personally identifiable information cannot be retrieved, even though it is present in the system so that data matches can be

made. This is the approach Ohio is considering for its new Education Management Information System.

PROTECTING CONFIDENTIALITY IN AN INFORMATION-SHARING ENVIRONMENT

Although special attention may be warranted when automated systems are used, in fact, assuring that individuals' confidentiality rights are protected is always important. Where consent is given, it does not nullify confidentiality rights; it is permission granted for a specific situation or set of situations. The affected agencies need to have policies and procedures in place that prepare and guide staff to share information responsibly and that recognize the continued need to respect confidentiality beyond the specific releases.

Staff Preparation and Guidance

As with any procedures that are both especially important and complex, any staff who will be in a position to share information as part of a collaborative endeavor should receive training. Training should address: the specific rules that govern the individual's own agency; at least in general terms the rules that govern collaborating organizations; and the provisions that have been established for sharing information.

In addition to training, staff will need written materials explaining the policies and procedures. Some agencies provide workers with a compilation of applicable confidentiality statutes. Whether or not this approach is used, it is not enough. The statutory language may not be comprehensible, will not reflect existing judicial or agency interpretations and may not give a worker meaningful guidance on how to address unusual situations. Materials written in plain English need to explain what the limits are, why they are there and acceptable, agreed-upon procedures for sharing information. The most effective guidance will seek to address specific situations that the worker is likely to face.

To complement training and written directives, there also should be an established way to resolve unclear situations. Without this, staff who are uncertain may be afraid to provide information at all or may simply base the decision on whether they trust the person asking for information. An interagency study of confidentiality in Oregon recommended designating a Confidentiality Resource Person in each department to respond to questions about releasing information.[15] In Florida's Department of Health and Rehabilitative Services, a standing Data Integrity/Security Control Board develops recommendations for needed changes in policies and procedures with respect to all data collected and/or stored by the department. Centralizing this responsibility is a way both to increase consistency in responses and to provide an upward flow of information about situations that may require further policy and procedure development. (The Oregon study went on to propose a standing *interagency* committee on confidentiality that could deal with problems as they were identified, either resolving them administratively or determining what legislative action would be needed.)

Finally, some collaborating organizations are reinforcing staff awareness of the need to handle confidential information responsibly by regularly putting the subject on staff meeting agendas, as is done in Santa Rosa County, Florida, or by having staff sign pledges or oaths. In Fulton County, Kentucky, such pledges provide both a basic foundation for information sharing and a routine reminder. Members of the inter-

agency team sign pledges when they first join the team and reaffirm those pledges in a shorter form at the start of every case conference. Sample oaths from Fulton County and San Diego are included in Appendix 3.

Limiting Exchange

Keeping the information that is exchanged to the *minimum* that is relevant and necessary to serve the child and family effectively is a good way to assure that open communication does not lead to an undue intrusion on privacy. Another helpful practice is to limit exchange to those who clearly *need to know* particular information about a child or family in order to provide desired services.

Many of the collaborative efforts mentioned in this report are explicit about the need to limit unnecessary discussion of confidential information. This was a guiding principle in the design planning of the envisioned Michigan Opportunity System, for example. In San Bernardino County's Children's Network, there is a statutory authorization for communication among members of a multidisciplinary team engaged in prevention, identification and treatment of child abuse. Despite this authorization, the established practice for case management presentations is that names of children are not to be used unless it is absolutely necessary for the protection of the child.

Fulton County, Kentucky, also expects staff to restrict exchanged information to that which is directly relevant. They further have agreed that exchange will take place orally only, in case-consultation meetings concerning affected children. Reducing the amount of paper that is exchanged is a good way to reduce the risk that material will be mishandled at some subsequent point.

Extra Safeguards for Particularly Sensitive Information

Because of negative public attitudes, there sometimes can be damaging repercussions if certain information about an individual becomes known. For this reason, it is essential that there be extra protection of information in the following categories: juvenile arrest records, human immunodeficiency virus (HIV) status, mental health history and treatment, and substance abuse history and treatment.

Re-Release of Information

Under federal regulations governing records in a number of areas, a recipient of information from the record may use it only for the purpose for which disclosure was made and may not disclose the information to any other party without prior consent of the affected individual.[16]

Many collaborative efforts that have addressed the confidentiality issue take a similar position with respect to any so-called "re-release" or "third-party release" of information, i.e., an organization that has *received* information in turn releasing it to another organization. Re-release is prohibited to keep dissemination within the accepted, limited boundaries and to assure that no one other than the organizations specifically authorized by the individual or family receives exchanged information. To help assure compliance with this prohibition, written information that is transferred often is stamped with a warning to this effect or is accompanied by a memorandum that explains the requirement.

THE LEGISLATURE'S ROLE

As we have suggested, it may be entirely possible to accomplish policy goals within existing law. However, some legislative actions might ease the process without altering substantive protections. For example, the Iowa legislature mandated that the Department of Public Health (DPH) should adopt rules to provide for sharing of information among agencies serving pregnant women and children. This put DPH in the position to develop model rules for other agencies to review and adopt to foster consistency.

In some instances, laws affecting different agencies are inconsistent not for any policy reason, but because the legislation was adopted at different times and had different drafters. Legislative review and action to reduce these inconsistencies can make it easier for collaborating organizations to adopt common policies, procedures and forms. This is the goal of a recommendation by the Oregon Departments of Education, Corrections and Human Resources in a 1991 report on the ways in which confidentiality rules impede service delivery. The report identified the need for a legislative mechanism to review all legislation relating to or containing proposals of client information sharing for the departments. The Oregon study also recommended that penalties for breach of confidentiality be made consistent and that the legislature ensure that state laws are brought into compliance with federal law and case law so that state law would accurately reflect permissible and impermissible sharing.[17]

Of course, the legislature ultimately will have responsibility if the collaborating organizations determine that substantive changes in statute are desirable. While many proposals may be acted on favorably, not all of them will be. Certain provisions of law create barriers to information sharing because a legislature has determined that there is a more important policy to be furthered. For example, a number of persons with whom we spoke expressed frustration at the strong confidentiality provisions contained in federal law relating to alcohol and drug treatment. In some cases, agencies clearly feel a tension between the best interests of a child and the prerogatives of a parent: the ability of agencies to help a child would be enhanced if information were available, but the parent does not want to make it available. Yet, Congress has made a policy decision that persons should be encouraged to come forward and seek treatment and has made the judgment that the willingness of persons to come forward would be diminished if there were not an assurance of confidentiality.

Where statutory barriers cannot be removed, collaborating organizations will need to explore alternative approaches that do not entail direct exchange of confidential information, perhaps similar to those that must be used when informed consent cannot be obtained.

CONCLUSION

For those who are undertaking broad-reaching collaborative efforts to improve the well-being of and outlook for children and families, confidentiality often looms as one of the first and seemingly most complicated "barriers" to joint action. What our research and conversations with state and local officials throughout the country have shown, however, is that confidentiality requirements are *not* the barrier that they might seem to be. Developing and implementing an effective approach for sharing information often takes longer than anyone had hoped and involves an attention to detail that sometimes may be frustrating. But the results of a careful, diligent and committed effort are clear — procedures that allow communication among organizations sharing a common concern for children and families, which significantly improve services for those children and families while also respecting their legitimate rights to privacy and confidentiality.

Yet, despite this promising finding, we recognize that many aspects of this important and complex issue remain to be addressed if the full potential of information sharing is to be realized. The scope, scale and aspirations of interagency collaboration today surpass anything of the past, and much of the necessary policy and operational framework still must be developed. Information exchange is one among a number of areas in which this further exploration and development will be particularly valuable. Forthcoming work by the Youth Law Center in San Francisco and others should help in this regard (see Appendix 5). So, too, will continued experimentation by and exchange of ideas among states and communities.

To help collaborators throughout the country learn from one another and to identify areas in which further clarification is needed, we encourage readers of this paper to share their questions and approaches with the organizations that have prepared this publication or with the National Center for Service Integration, a federally funded resource center created to provide technical assistance and information dissemination services on the subject of cross-sector collaboration.

National Center for Service Integration
154 Haven Avenue
New York, New York 10032
212-927-8793

Joining Forces
One Massachusetts Avenue N.W., Suite 700
Washington, D.C. 20001-1431
202-336-7079

Council of Chief State School Officers
One Massachusetts Avenue N.W., Suite 700
Washington, D.C. 20001-1431
202-408-5505

American Public Welfare Association
810 First Street N.E., Suite 500
Washington, D.C. 20002-4267
202-682-0100

Center for Law and Social Policy
1616 P Street N.W., Suite 450
Washington, D.C. 20036
202-328-5140

Education Commission of the States
707 17th Street, Suite 2700
Denver, Colorado 80202-3427
303-299-3600

APPENDICES

APPENDIX 1

Sample Release Forms

Following are examples of release forms being used by various collaborative efforts around the country. These may provide a useful starting point in designing your own release forms. However, it is important to remember that each state or community developing an approach for the exchange of information must determine individually the content of a form that will be legally sufficient under applicable laws and regulations.

CONTRA COSTA COUNTY, CALIFORNIA

COUNTY OF CONTRA COSTA

INTERAGENCY FAMILY PRESERVATION PROGRAM

Authorization to Release Information

I, _____, hereby authorize release of
(please type or print name)
all records, documents, and information on my son, daughter, and myself and/or my family which is or may come on file with Contra Costa County Mental Health Department, Social Service Department, Probation Department, local school agency and Families First to and between these agencies for their utilization when meeting and planning services through their Interagency Referral Committee. I may revoke this consent at any time by notifying the Interagency Referral Committee in writing of my desire to withdraw the consent given herein.

_____ _____
Signature of Consenter Date

_____ _____
Witness Date

_____
Agency and Title of Witness

BW:jap
MOU.FP:FPMOU.FIN

CONSENT TO TREATMENT
AND
CONSENT FOR RELEASE OF CONFIDENTIAL INFORMATION:
BLUEGRASS INTERAGENCY MOBILIZATION
FOR PROGRESS IN ADOLESCENT AND CHILDREN'S TREATMENT
INTERAGENCY INFORMATION EXCHANGE

I, _____, hereby declare that I am the parent _____ or guardian _____ of _____, who is a child (SS# __ __ __ - __ __ - __ __ __ __) applying for services provided by Bluegrass IMPACT, a project of the Cabinet for Human Resources and the Bluegrass Regional Mental Health/Mental Retardation Board, Inc. I hereby give permission to those agencies or providers affiliated with Bluegrass IMPACT, a listing of which has been given to me, to provide services to my child including consultation with agencies which may not have had direct contact with my child.

I recognize that the services for my child's condition require the collaboration of numberous agencies and service providers. I understand that this collaboration requires the disclosure of information about my child so as to help the various service providers to make necessary assessments and service plans.

I understand that the following information may be released to service providers:

1. The full name and other identifying information regarding my child and our family.

2. Diagnostic and assessment information including psychological and psychiatric evaluations, medical histories, educational and social histories. These evaluations may include references to other family members.

3. Treatment and/or educational rehabilitation or habilitation plans.

4. Current observations of behavior.

5. Recommendations to other providers.

The purpose of this disclosure shall be to facilitate service delivery to my child.

I further understand that the information generated or obtained by the project can be shared with the agencies or providers affiliated with the project.

This authorization to release information extends to the various interagency committees and response teams of project IMPACT. I authorize data to be shared with the Cabinet for Human Resources, Department for Mental Health and Mental Retardation Services, Division of Mental Health. The purpose of this disclosure is to assist in needs assessment and planning for future services.

I also understand that this authorization for release of information will be in effect for the duration of services provided to my child and will expire upon termination of services. I understand that I can revoke this consent at any time and this consent shall be reviewed annually.

Affiliated Agencies and Providers

_____ Department of Social Services
_____ Division of Mental Health
_____ Comprehensive Care Center
_____ Kentucky Court System
_____ School Districts: _____
_____
_____ Health Departments
_____ Urban County Government Children's Services
_____ Private Therapist: _____
_____ Psychiatric Hospital Unit: _____
_____ Therapeutic Group Home: _____
Other: _____
_____
_____
_____

I certify that I have read and understood the content of this form.

_____ _____
Parent or Guardian Date

_____ _____
Witness Date

REVOCATION REQUEST:

I hereby revoke the authorization for release of information pursuant to the terms above.

_____ _____
Parent or Guardian Date

_____ _____
Witness Date

EXAMPLE OF LIMITED AUTHORIZATION TO RELEASE CONFIDENTIAL INFORMATION

CONSENT TO PARTICIPATE AND AUTHORIZATION TO RELEASE CONFIDENTIAL INFORMATION

I. PROGRAM PURPOSE: (Statement must answers who, what and why)

The **Center** is a service jointly funded and governed by city, county, private and school agencies for families and children served by the school. The names of participating agencies and programs are: (Specify the names of the agencies/programs must be stated to assure the participant is properly informed.) All have agreed to cooperate to better serve you and your child(ren) and to protect your confidential records. The purpose of the **Center** is to provide families the support they need to enable their child(ren) to achieve maximum academic, social and personal growth; and to assist families in obtaining health, education, social and community services as needed.

II. REASON FOR LIMITED RELEASE: (Statement must give the purpose of the release)

Center staff and staff from the participating agencies (hereafter called **Extended Team**) who work at or with the **Center** need to communicate with each other on your behalf. Your initials and signature on this form gives your written consent for **Center** staff and the **Extended Team** to verbally share certain information on your family circumstances. This release also gives designated **Center** staff permission to review and record certain information from the automated files of the participating agencies. The purpose is to: better coordinate services between the **Center** and participating agencies who can or are providing services to you, your child(ren), or your family; minimize duplicate efforts by you and the staff working on your behalf to verify certain facts about the family held by a participating agency; and develop the best service plan for and with you.

III. PARTICIPANT AGREEMENT/AUTHORIZATION: Initial the black line(s) to acknowledge you have read, understand, and agree with the statements.

____. I wish to receive services from the **Center** for my child(ren) enrolled in the school, myself, and other members of my family for whom I am the parent or guardian.

____. I authorize **Center** case management staff and **Extended Team** members from the participating agencies to verbally exchange the following personal information only about me and my minor child(ren) from their case files: (Identify the information to be exchanged.)

> Example statement: Summary information about the agency(s) service plan for health, education and social services, and the level of achievement of the plan(s). Summary is defined as general statements only and precludes diagnosis and specific treatment information on any services given by a health care provider and any information specifically precluded by law under this simplified procedure.

____ I authorize **Center** staff to access and record information from the automated files of participating agencies to verify the personal information noted below: (Identify the data elements and information to be released)

Examples of data elements: Name; birthdate; sex; address; social security number; case worker number, name and phone number; and case status - open or closed with date of last action.

IV. NOTICE OF RIGHTS: (State limits on release and other required assurances and notifications according to the service delivery plan)

Your records at the **Center** and with the participating agencies are protected under the federal, state and local regulations governing Confidentiality. Written records from those files will not be released under this authorization; except as permitted or required by law. **Center** staff may release information on you or the child(ren) in your legal custody without your signed consent if you or the child(ren) are in imminent danger to yourself or others and in the instance of child, elder or dependent adult abuse.

The discussions and consultations of the **Center** staff and **Extended Team** on families served at the **Center** are confidential and the information may not be released to anyone other than designated **Center** or **Extended Team** staff. The information will be maintained in a manner that ensures protection of your privacy and confidentiality rights.

Federal rules restrict any use of the disclosed drug or alcohol information to criminally investigate or prosecute you.

You may revoke this consent at any time. Exception: Action already taken based on the consent, may not be revoked.

This consent expires one year from the date you sign this form.

You are entitled to a copy of this agreement.

SIGNATURE _____ DATE ___|___|___
(Parent/Guardian/Authorized Minor Mo Day Year

SIGNATURE _____ DATE ___|___|___
(Authorized **Center** Staff) Mo Day Year

Citation Examples: Civil Code, 34, 56 and 1798
Welfare and Institutions Code, 10850 and 5328
Education Code, 49073
42 CFR Part 2
Health and Safety Code 1795

PRINCE GEORGE'S COUNTY INFANTS AND TODDLERS PROGRAM
CONSENT FOR PARTICIPATION

I wish to have my child, _____, referred to the Prince George's County Infants and Toddlers Program. The Infants and Toddlers Program represents a cooperative effort between the following agencies:

- Prince George's County Public Schools
- Prince George's County Health Department
- Prince George's County Department of Social Services
- Prince George's County Association of Retarded Citizens
- Prince George's County Commission for Persons with Disabilities, and
- Prince George's County Commission for Families, and
- Other _____

I, _____, have received all information relevant to the program.

____ I agree to participate.
____ I agree to have my child evaluated.
____ I agree to family assessment.

I understand that information obtained by the Infants and Toddlers Program will be shared and used for screening, assessing, planning, and facilitating the delivery of appropriate services under this program. The agencies participating in this program will exchange my child's records with the understanding that they are confidential and will not be released without my prior written consent, except to participating agencies and to the Maryland Office for Children, Youth, and Families. I understand that the agencies listed above will share pertinent records, including but not limited to the following:

- educational evaluations and services
- medical evaluations and treatments
- psychological evaluations and treatments
- social history
- developmental history
- other pertinent agency records about my child
- other (specify)_____

Comments:_____
_____
_____

I further understand that I have the right to review and obtain a copy of such records, and that my granting of consent is voluntary and I may withdraw my consent at any time by submitting a signed and dated waiver revoking my consent.

_____ _____
Signature of Parent(s) or Guardian(s) Signature of Witness

_____ _____
Type or print name Type or print name

_____
Date

Form #4 [7/91]

SAN BERNARDINO COUNTY
CHILDREN'S NETWORK

CONSENT TO EXCHANGE CONFIDENTIAL INFORMATION

Patient's Name_____ Birthdate_____

Social Security Number_____ Chart Number_____

I authorize San Bernardino County Department of _____ _____ to exchange information with:

NAME _____

_____

_____

_____

about information obtained during the course of my treatment for _____

_____.

The exchange of records authorized herein is required for the following purpose:

_____.

Such exchange shall be limited to the following specific types of information:

_____

_____.

This consent is subject to revocation by the undersigned at any time except to the extent that action has been taken in reliance hereon, and if not earlier revoked, it shall terminate, without express revocation on:

_____.
(Date, Event, or Condition)

Date:_____ Witness:_____

Signed:_____ Signed:_____
Patient Physician in Charge

Signed:_____
Parent,Guardian, Conservator

CONFIDENTIAL PATIENT INFORMATION:
SEE CALIFORNIA WELFARE AND
INSTITUTIONS CODE SECTION 5328

LINN COUNTY, OREGON

ALBANY YOUTH SERVICES TEAM
AUTHORIZATION FOR RELEASE AND EXCHANGE OF INFORMATION

I, _____, authorize the release of information between and among
Parent/Guardian Signature

the identified Albany Youth Services Team members which will be planning services for

_____.
Client(s) Name(s) (Please include all family members)

The purpose of the Authorization Form is to enable agencies identified as members of the Albany Youth Services Team to better serve your child through coordinated service planning and delivery. Representatives of these agencies will meet and share information regarding your child at scheduled planning and review meetings.

The Albany Youth Services Team for your child shall include the following agencies:

* Greater Albany Public Schools
* Children's Services Division, Linn and Benton Counties
* Linn and Benton County Alcohol & Drug Treatment Programs
* Linn County Dept. of Health Services
* Linn-Benton Education Service District
* Adult and Family Services
* Linn and Benton County Juvenile Department
* Albany Police Department
* Linn and Benton County Sheriff's Department
* Oregon State Police
* State of Oregon Parole and Probation
* Other_____

To assist in determining the availability of resources, please put a check in the box if your child has a:

☐ Medical Card or ☐ Private Insurance

The information which may be disclosed/exchanged is: presence in the program, and school, legal and treatment records which include assessment, family history, diagnoses and treatment recommendations from the Linn County Mental Health and Alcohol and Drug Treatment Programs.

This release authorizes a free exchange of information between members in order to give the most complete and thorough services available. It does not authorize release to any other person or agency except those agencies listed above. Unless revoked in writing, this release and exchange shall remain in force for a period of 12 months from the date of authorization.

To the party receiving this information: This information has been disclosed to you from records whose confidentiality is protected by federal law. Federal regulation (42 CDR Part 2) prohibits you from making any further disclosure of it without the specific written consent of the person to whom it pertains, or as otherwise permitted by such regulations. A general authorization for the release of medical or other information is not sufficient for this purpose.

_____ _____
Witness Authorizing Signature

_____ _____
Date Relationship to Child

_____
Juvenile's Signature (12 and over)

ALBANY YOUTH SERVICES TEAM
REFERRAL FORM

Youth's Name _____ DOB ___/___/___ Age _____ Sex M / F

Home Address _____ Phone (Home) _____ Phone (Work) _____

Referred By _____ Agency _____ Date Referred _____

School _____ Grade _____ Spec. Ed. Yes / No Attending Yes / No Academic Working Level At / Above / Below

Parent/Guardian Name _____

Address (If different from above) _____

Youth Lives With Father / Mother / Step Parent / Foster Parent / Adopted / Other (explain): _____

Reason for Referral: _____

Pertinent Family History and Observations: _____

Additional Comments/Information: _____

(Include any specific questions you have of particular agencies in below categories.)

Prior Agency Involvement: _____

Request for Other Agency Participation in YST Staffing: _____

(Please make sure any agencies listed above are also listed on the Parent Authorization Form.)

Revised 1/91

FULTON COUNTY KIDS PROJECT
(KENTUCKY INTEGRATED DELIVERY SYSTEM)

Student Identification:

Name:_____DOB:_____
Address:_____S.S.#:_____
Parent:_____Phone:_____
Address (if different from student):_____

Permission for Service:

Permission is hereby given to the staff of the agencies participating in the **Fulton County KIDS Project**, as listed below, to render services to:_____
whose relationship to me is:_____Child _____Other:_____

Release of Information:

I, as parent/guardian of the above named child, hereby consent to the release of information by the participating agencies within the **Fulton County KIDS Project** for oral presentation only at case conference meetings. This information will not be released to other non-participating agencies/persons without the express written consent of the parent/guardian and prior written notification of the school district. I understand and have had explained to me that the sharing of information will enable the participating agencies to provide my child/family with the most efficient and effective services. This release may be withdrawn upon receipt by the school district of the written notification of revocation.

This consent form is valid for a period of time beginning _____and ending_____

_____ _____
Parent/Guardian Signature Date

_____ _____
Witness Date

I understand that the following agencies will be participating as needed in the case conference and will be exchanging oral information concerning my child/family:

Department of Vocational Rehabilitation
Department for Social Services
Department for Social Insurance
Purchase District Health Department
Commission for Handicapped Children
Department for Employment Services
Administrative Office of the Court-Juvenile Services Division
Western Kentucky Regional Mental Health-Mental Retardation Board, Inc.
Fulton County School District
Fulton Independent School District

APPENDIX 2

Sample Checklist for Staff Responsible for Obtaining Consent

( ) THE DELAWARE INTEGRATED SERVICE INFORMATION SYSTEM (ISIS) is a computerized statewide tracking system for children at risk. "At-risk" children are children from newborn to eight years old whose parents or doctors are concerned about their growth and development. Private doctors, hospitals, and agencies are working together to make ISIS work for you.

( ) THE PURPOSE OF ISIS IS to better plan services for children; to coordinate services to babies and young children; to work toward having services available for children as early in life as possible. Some of these services are: audiology, speech/language, nursing, nutrition, occupational therapy (OT), physical therapy (PT), psychological, social work, special instruction in school.

( ) ISIS WILL HELP CHILDREN AND THEIR FAMILIES by helping families who receive many services understand what they are getting; helping families when children change from one program to another; by making sure all your information about services received is available to you at any time; by helping to avoid duplication of services; by helping professionals to help families find services for their children and themselves.

( ) THE ONLY INDIVIDUALS AGENCIES WHO WILL BE ALLOWED TO LOOK AT THE INFORMATION are those listed on the front of the Consent for Release of Information form you signed. You may add others, or refuse permission to any one of the listed agencies. Only those agencies or individuals who are providing services to your child and your family would have a need or interest in viewing your information.

( ) THE KIND OF INFORMATION THAT WILL BE ENTERED INTO THE ISIS SYSTEM will be information that makes it possible to keep track of the services your child and family receives, for example: name, address, phone, risks for developmental delay, medical diagnosis, plan of service, referrals. Information from private, confidential conversations you may have with any individual working with you and your family will not be part of this computer information.

( ) YOU MAY ASK AT ANY TIME WHICH INDIVIDUALS OR AGENCIES ARE LOOKING AT INFORMATION ABOUT YOUR CHILD and you have the right to change the list of those able to share information about your child at any time.

****

( ) I NEED TO KNOW THAT I HAVE EXPLAINED THIS PROGRAM TO YOU CLEARLY, AND THAT YOU UNDERSTAND IT, so would you please tell me:

( ) How do you think ISIS works? (let him/her explain in his/her own words - without prompting).

( ) What benefits do you expect to get from participating in ISIS?

( ) HAVE YOU MADE SURE THE PARENT UNDERSTANDS EVERYTHING YOU HAVE SAID?

_____

Signature of Agency Individual Obtaining Consent to Participate in ISIS

PLEASE ASK PARENTS

Yes	No	
[ ]	[ ]	I would like to be part of a state-wide parent-to-parent network for support and sharing of information. Therefore please release my name and address to the Parent Information Center of DE., Inc.

1/7/92

APPENDIX 3

Sample Staff Oaths

FULTON COUNTY, KENTUCKY

KENTUCKY INTEGRATED DELIVERY SYSTEM

INITIAL CASE CONFERENCE TEAM MEMBERS
CONFIDENTIALITY STATEMENT

I, as a member of the initial case conference team participating in the Kentucky Integrated Delivery System, understand that confidentiality of identifiable information shall be maintained according to Part V, Privacy Act of 1974 and the Kentucky Revised Statutes on Confidentiality: (KRS 194.060, KRS 200.490, KRS 210.235, KRS 210.670, KRS 222.270)

The oral information presented at case conference meetings will not be released to other non-participating agencies/persons without the express written consent of the parent/guardian.

SIGNATURE	AGENCY
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

DATE_____

EXAMPLE OF CONFIDENTIALITY OATH

CENTER STAFF OATH OF CONFIDENTIALITY

I, the undersigned, hereby agree not to divulge any information or records concerning any participant without proper authorization in accordance with state and federal law and interagency agreement(s). I recognize that any discussion of or release of information concerning a participant to any **unauthorized person** is forbidden and may be grounds for legal and/or disciplinary action.

During the performance of my assigned duties, I will have access to confidential information required for effective family services coordination and delivery. I agree that all discussions, deliberations, records and information generated or maintained in connection with these activities shall not be disclosed to any **unauthorized person.**

I recognize that unauthorized release of confidential information will (Cite regulatory provision regarding penalties. Example: exposes me to personal civil liability under the provisions of Welfare and Institutions Code, Section 5330; and potential fine under Title 42, Code of Federal Regulations, Part 2).

Executed this _____ day of _____, 19___, at _____.

SIGNATURE:_____ NAME (Print):_____

Center Employee

TITLE:_____

APPENDIX 4

Some Key Federal Statutes and Regulations Concerning Confidentiality of Information

Aid to Families with Dependent Children Program
42 U.S.C. §602(a)(9); 45 C.F.R. §205.50

Alcohol and Drug Abuse
42 U.S.C. §290ee-3 (drug abuse)
42 U.S.C. §290dd-3 (alcohol)
42 C.F.R. Part 2

Computer Matching and Privacy Prevention Act
5 U.S.C. §552a

Early Intervention Program for Infants and Toddlers (Part H of the Education of the Handicapped Act)
20 U.S.C. §1480(2); 34 C.F.R. §303.460

Family Educational Rights and Privacy Act ("Buckley Amendment")
20 U.S.C. §1232(g); 34 C.F.R. Part 99

Federal Child Abuse and Prevention and Treatment Act
42 U.S.C. §5101 et. seq.; 42 C.F.R. §1340.14(i)

Food Stamp Program
7 U.S.C. §2020(e)(8); 7 C.F.R. §272.1(c)

Foster Care and Adoption Assistance
42 U.S.C. §671(a)(8)

Freedom of Information Act
5 U.S.C. §552

Juvenile Justice & Delinquency Protection
42 U.S.C. §5676

Maternal and Child Health Services Block Grant
42 C.F.R. §51a.6

Medicaid Program
42 U.S.C. §1396a(a)(7); 42 C.F.R. §431.300

Privacy Act
5 U.S.C. §552a

Runaway and Homeless Youth
42 U.S.C. §5731

School Lunch Program
42 U.S.C. §1758(b)(4); 7 C.F.R. §245.8(a), (b)

Special Education (Part B, Individual with Disabilities Education Act)
20 U.S.C. §1412(2)(D); 20 U.S.C. §1417(c); 34 C.F.R. §300.129; 34 C.F.R. §300.560 - 300.576

WIC Program
42 U.S.C. §1786; 7 C.F.R. §246.26(d)

Youthful Offender Act
18 U.S.C. §5038

APPENDIX 5

Additional Resources on Confidentiality

Hobbs, Lola J. *Tackling the Confidentiality Barrier: A Practical Guide for Integrated Family Services.* San Diego, September 1991.

This report — prepared for San Diego's collaborative New Beginnings initiative — reviews federal, California and local San Diego statutory and regulatory requirements for managing confidential information across publicly funded health, education and social service programs. The report analyzes the issue, suggests management strategies to minimize problems, offers model procedures and forms and recommends changes in law and administrative policy to facilitate responsible exchange of information. Appendices contain compilations of relevant federal, state and local statutes and regulations.

Copies of the report and appendices are available from:

Department of Social Services
County of San Diego
Community Relations Bureau, Room 843
1255 Imperial Avenue
San Diego, CA 92101-7439
619-338-2860

The report is $6.50, Appendix A containing federal and California citations is $9.00, and Appendix B containing local citations is $11.50. Checks should be made payable to "County of San Diego."

Legal Action Center. *Handbook: Legal Issues for School Based Programs.* New York, 1991.

This handbook is written for agencies providing alcohol and drug treatment and prevention services for students. It includes a discussion of federal alcohol and drug abuse regulations, issues in structuring a student assistance program, and issues with respect to the relationship between a student's right of confidentiality and a parent's right to information under the Federal Educational Rights and Privacy Act (FERPA).

Copies of the report may be purchased for $26.95 from:

Legal Action Center
153 Waverly Place
New York, New York 10014
212-243-1313

Bulk rates are available.

Mental Health Law Project; National Early Childhood Technical Assistance System; and Division for Early Childhood of The Council for Exceptional Children. *Strengthening the Role of Families in States' Early Intervention Systems: Policy Guide to Procedural Safeguards for Infants and Toddlers and Their Families Under Part H of the Education of the Handicapped Act.* Washington, D.C., 1990.

This document describes the law and presents a set of proposed policies for addressing issues of consent, notice of rights, rights to review and correct records, confidentiality and procedures for resolving parental complaints in the implementation of systems of early intervention services for infants and toddlers under Part H of the Education of the Handicapped Act. Many of the procedural safeguards identified may have general applicability to other programs serving children and families.

Copies may be purchased for $17.50 including postage, or $12.00 each for orders

of 10 or more shipped to the same address. To order contact:

Division for Early Childhood/Council for Exceptional Children
Publication Sales
1920 Association Drive
Reston, Virginia 22091-1589

National Academy of Sciences, Committee on National Statistics, Panel on Confidentiality and Data Access

The Committee on National Statistics and the Social Science Research Council have jointly convened a panel to study issues of confidentiality and data access and to provide recommendations to federal agencies for better accommodating the increasing tension between data access and confidentiality. This study focuses almost entirely on statistical agencies and on statistical and research uses of data. Many of the issues being considered by the Panel may have general applicability to state, local and nongovernmental agencies establishing policies regarding the handling of confidential materials. At this time, it is anticipated that a report will be available through the National Academy Press in late 1992. Contact:

Committee on National Statistics
National Academy of Sciences
2101 Constitution Avenue N.W.
Washington, D.C. 20418
202-334-3096

National Association of Social Workers, Commission on Education. *Position Statement: The School Social Worker and Confidentiality.* Silver Spring, Maryland, 1991.

This position statement describes general ethical and legal issues facing school social workers, with particular attention to situations that frequently arise in the school setting. The document includes references and an annotated bibliography. Copies are available at no charge from:
National Association of Social Workers
750 First Street N.E.
Washington, D.C. 20002

Oregon Departments of Education, Corrections, and Human Resources. *A Study of Confidentiality as a Barrier to Service Delivery.* Salem, April 1991.

This study by an interagency workgroup contains analysis and recommendations based on staff interviews to determine service barriers caused by confidentiality. The report identifies possible administrative, legislative and judicial actions to reduce the barriers, including changes that could be implemented at the service delivery level.
Copies may be requested from:

Barbara Ross
Department of Human Resources
Director's Office
320 Public Service Building
Salem, Oregon 97310

Youth Law Center

The Center is undertaking an in-depth analysis of statutes and regulations pertaining to confidentiality in four states. The results of this study, which is being conducted with support from the Ford Foundation, will be available in late 1992. Contact:

Youth Law Center
114 Sansome Street, Suite 950
San Francisco, California 94104-3820
415-543-3379

NOTES

1. See 45 C.F.R. §205.50; *Michigan Welfare Rights Organization v. Dempsey*, 462 F. Supp. 227 (E.D. Mich. 1978).

2. See 42 U.S.C. §290dd-3(c); 42 U.S.C. §290ee-3(c).

3. For a thoughtful discussion of the concept of "informed consent," see: "Informed Consent in Social Work" by Frederic G. Reamer, *Social Work* (September-October 1987), pp. 425-429.

4. For additional information about interagency communications concerning undocumented persons, contact the National Immigration Law Center, 1636 West Eighth Street, Suite 205, Los Angeles, CA 90017.

5. 42 C.F.R. §2.31(a)(9).

6. 42 C.F.R. §2.31(a)(8).

7. 34 C.F.R. §300.574.

8. See, e.g., 34 C.F.R. §99.36 (authorizing release of information by educational agency necessary to protect health and safety of the student or other individuals).

9. Sid Gardner and Katherine Kates, "The Issue of Confidentiality in Programs for Children and Youth," September 6, 1989 (unpublished manuscript).

10. 34 C.F.R. §99.31(a)(6).

11. The Federal Computer Matching and Privacy Protection Act imposes a number of requirements when computer matches are used for such purposes as establishing or verifying eligibility or continued compliance with requirements for federal benefits programs. However, the law does *not* apply in the following situations: when a match is performed to produce aggregate statistical data without personal identifiers; or when a match is performed to support a research or statistical project and the specific data will not be used to make decisions concerning the rights, benefits or privileges of specific individuals. See 5 U.S.C. 552a(a)(8)(B)(i)(ii).

12. Some jurisdictions may wonder why, in the instance just cited, the exchange could not go the other way, with the welfare department opening its records for the school to do the match, since the agency currently may be confirming children's receipt of AFDC or Food Stamps to certify needy children for free or reduced-price school meals. The reason is that a *specific exception* has been made permitting this type of release without prior consent for the purpose of establishing eligibility for the school meal programs, so long as the school's standards of confidentiality are similar to those of the welfare agency. The U.S. Department of Health and Human Services (DHHS) has permitted this exception based on its interpretation of the language of the National School Lunch Act

[42 U.S.C. §1758(b)(2)(C)(II)]. The DHHS position is contained in the following interpretive policy memos: FY91-OFA-18 (September 5, 1991) and FY91-AFDC-35 (May 2, 1991).

13. This approach was suggested by Robert Veatch, Director of the Joseph and Rose Kennedy Institute of Ethics at Georgetown University, in a letter to Janet Levy, dated December 5, 1991.

14. 45 C.F.R. Part 46, Public Welfare, Protection of Human Subjects.

15. Oregon Departments of Education, Corrections, and Human Resources, *A Study of Confidentiality as a Barrier to Service Delivery* (April 1991), p. 19.

16. See, for example, regulations governing education records at 34 C.F.R. §99.33.

17. Oregon Department of Education et al., *A Study of Confidentiality*, pp. 23-24.

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